

Executive Summary

At the direction of Governor Frank O'Bannon, the Indiana Family and Social Services Administration has aggressively pursued reform for all of the at-risk populations for which it provides services. Despite this level of effort, Indiana continues to lag behind the rest of the country in providing a comprehensive array of long-term care services that includes not only the traditional health care service settings, but also affordable housing and sufficient in-home and community-based service options. This array of services is critical for facilitating consumer choice and independence, and promoting quality of care and quality of life for Hoosiers who are at risk for, or already in need of, long-term care services.

Persons who utilize long-term care services (regardless of funding source) include: the frail elderly; adults and children with physical disabilities; adults and children with developmental disabilities; adults and children with mental illness; and children and their families who are at risk of involvement in the child protective system, the juvenile justice system, or through academic failure in the education system.

There continue to exist a number of significant obstacles that make reform of Indiana's long-term care service delivery system in Indiana so difficult to accomplish. Namely, affordable housing and community care services are extremely limited, making true consumer choice generally unavailable. Similarly, services and funding opportunities for children who are seriously emotionally disturbed or who are considered to be at risk of abuse, neglect, delinquency, developmental delay, developmental disability or academic failure in Indiana are not available or are not managed consistently in each of Indiana's 92 counties.

To increase the momentum for expanding community capacity and consumer choice, the Indiana Family and Social Services Administration, in an unprecedented effort, has teamed up with the U.S. Department of Health and Human Services to pursue innovation and lasting change. Three federal grants, developed in response to the landmark disability decision, *Olmstead v. L.C.*, have been sought, and subsequently awarded, to assist Indiana in once-and-for-all overcoming the long-standing barriers that have made reform so elusive.

The three grants are as follows:

- *Real Systems Change Grant.* The purpose of this grant is to: establish a Commission that will provide a constant forum for interaction with consumers of long-term care services and their advocates; identify best practices and barriers to community integration and consumer control; provide oversight and monitoring; assist in the implementation of a series of mini-grants to local communities; and make further recommendations for policy and funding actions.
- *Nursing Home Transitions Grant.* The purpose of this grant is to: develop models for diversion from, and transition and of nursing home residents back into the community; provide training, education, and outreach; collaborate with nursing home associations, housing partners, assisted living facilities, and community stakeholders; develop a team to design and facilitate the transition process; identify and select candidates to be transitioned and/or diverted; and evaluate and prepare reports.
- *Community Personal Assistance Services and Supports (CPASS) Grant.* The purpose of this grant is to: provide outreach and information about consumer-directed care services; develop

a consumer-directed personal assistance services model and the supporting infrastructure; establish a fiscal intermediary structure for the attendant care workers; provide enhanced training; develop quality assurance, conflict resolution, and emergency assistance protocols; and develop a system for outcomes-based reporting.

At the lead in this effort, is the appointment by Governor O'Bannon of a bi-partisan, broad-based Commission, representing experts in fields that have never before been convened, to direct and coordinate the elements of long-term care in Indiana that have long been disconnected.

The Commission is funded primarily by the Real Systems Change Grant, but also receives funds from the Nursing Home Transitions and Community Personal Assistance Services and Supports grants for its role in coordinating all three initiatives; it uses no state funds.

The Commission's primary purpose is to develop short and long-term strategies to create or expand community options for persons at risk of being institutionalized, or for those currently in a nursing home or other institutional setting within Indiana's long-term care service delivery system. Its specific functions include: identification of the policy issues surrounding institutionalization; compilation of key statistics and other resource materials; identification of successful and innovative programs that break traditional housing and service barriers; solicitation of consumer perspective; and development of funding and policy strategies. Its work is intended to complement, and not duplicate, the valuable work already accomplished by so many others. It is scheduled to meet monthly for a twelve to eighteen month period, and produce both an interim and a final report for the Governor.

The Commission has convened five special task forces that are devoted to specific policy areas of concern, and a Consumer Advisory Committee specifically designed to research and evaluate the relevant policy issues, advise the Commission, and increase the scope and substance of Hoosier participation in formulating the solutions needed to break new ground in Indiana.

The Commission is also working with the Indiana Family and Social Services Administration to develop and award a number of mini-grants funded through the Real Systems Change Grant. These mini-grants are designed to create community partnerships, provide incentives for public/private partnerships, and serve to encourage innovation at the community level between community stakeholders.

The mini-grants are directed to the three major goals of the Commission:

- To develop community capacity in the areas of community living arrangements, affordable housing, transportation, supported employment, and caregiver support.
- To develop systems that support consumer choice and consumer-directed care.
- To develop innovative systems that help to identify and propose solutions to eliminate barriers to service.

By the Commission's third meeting in September 2002, it became clear that the original assignments and time-lines established for both the Commission and its task forces were not responsive enough to the urgency of many of the system problems and the opportunities presented by the upcoming legislative session. As a result, the Commission decided to deviate from its original workplan and instead refocus the task forces on identifying the most significant of the long-term care service delivery barriers and to develop comprehensive recommendations in response. Each recommendation that was subsequently developed was then assigned to one of three categories: those that should be implemented quickly and with little or no fiscal impact or

regulatory requirements; those that should be implemented quickly but are accompanied by a fiscal impact and/or regulatory changes; and those that are more complex, costly or otherwise difficult that will take more time to develop and implement.

Despite extremely challenging time-lines, the task forces were able to develop a list of recommendations for each of the three categories. Time constraints required them, the Consumer Advisory Committee, and the Commission to focus their attentions on the recommendations in the first category, those that should be implemented quickly and with little or no fiscal impact or regulatory requirements. The focus of this Interim Report is to highlight sixteen (16) specific recommendations that have been identified and studied. Each has been grouped according to one or more “themes,” which include: eligibility; streamlining or maximizing funding; developing provider incentives to increase capacity; consumer education; and consumer choice. They are not presented in priority order, but instead are considered collectively to be critical to the overall reform needed to develop community capacity in Indiana.

Another nineteen (19) recommendations have been identified and are scheduled for deliberation and analysis over the next six months. The Commission will continue to work through the five task forces and the Consumer Advisory Committee on their development. Once evaluated they will be presented formally for the Governor’s consideration in the final report due in June 2003.

The Commission strongly advises the Governor and the legislature to take action on the recommendations. Each is critical in achieving the long-term care reform that has so long been envisioned by the Governor and so many others, and each is relatively simple to implement.

For the remainder of its appointment, the Commission will work with the Indiana Family and Social Services Administration to fully develop the additional recommendations that have been identified, oversee the mini-grant award process, develop focus groups, consider additional expert testimony, identify and document “best practices”, fully develop a long-term care housing and services fact book of statistics and relevant information, develop strategies for capacity building, and define the benchmarks needed to measure change.

The Commission would be remiss if it failed to mention how much work remains to be done. For despite the activity and the level of progress that has been made by the Indiana Family and Social Services Administration and other state and local agencies over the past few years, Indiana continues to remain significantly behind most other states in re-focusing its scarce resources on more desirable, less costly community-based service delivery options. Spending priorities in Indiana continue to focus on institutional care, and progress in resolving many of the more complex service delivery problems such as caregiver support, eliminating process and system barriers, understanding the needs and desires of consumers, and shortage of caregivers, for example, has been frustratingly slow. Furthermore, the common framework for health care that is provided in traditional institutional settings and that favors medically cautious modes of care over one that relies upon consumer independence and freedom of choice continues to be extremely difficult to change. The Commission accepts this current reality but commits itself to being part of the solution.

Chapter 1: Introduction

Beginning in the early 1990's, Indiana earnestly began to pursue a shift of long-term care service delivery away from the traditional, institutional settings of state-operated facilities, nursing homes, intermediate care facilities for the mentally retarded, and group homes, in favor of the then less-familiar community setting. It began with the controversial closing of Central State Hospital in 1992, which was later applauded for the significant, positive outcomes achieved for so many of its residents who were previously believed to be unable to function successfully in the community.

Many changes have occurred since that time. At the direction of Governor Frank O'Bannon, the Indiana Family and Social Services Administration has aggressively pursued reform for all of the at-risk populations for which it provides services. Medicaid community programs have been expanded, state-operated facilities have been closed, eligibility for the Medicaid disability program has been expanded, uninsured children of working parents are now receiving health care, services for persons with mental illness have been expanded, and more.

Despite this level of effort, however, Indiana continues to lag behind the rest of the country in providing a comprehensive array of long-term care services that includes not only the traditional health care service settings, but also affordable housing and sufficient in-home and community-based service options. A full array of services is needed in order to facilitate consumer choice and independence, and to promote quality of care and quality of life for Hoosiers who are at risk for, or already in need of, long-term care services. It is noteworthy that a nationally recognized consultant in the long-term care field recently predicted that, at current rates of growth, Indiana would not have a balanced long-term care system, where consumers have real choice in selecting community care settings, for another 30 to 40 years.¹

Evidence of this service gap is the large proportion of Indiana's frail elderly and persons with disabilities who continue to remain in institutions. This imbalance was created by years of institutional bias, driven by both federal and state regulation, and a general resistance to changing from what has been considered by many to be a very "safe" medical model of care to one that favors consumer choice and independence, which includes some level of health care "risk."

There are a number of significant obstacles that make reform of its long-term care service delivery system in Indiana so difficult to accomplish. Affordable housing and community care services in Indiana are extremely limited, making true consumer choice generally unavailable. There is, in fact, no publicly-funded adult program in Indiana that operates without a waiting list for persons in need of that/those services. Specific examples of programs whose demand far exceeds the supply are: the state-funded CHOICE Program; Medicaid Home and Community Based Services Waivers; and Section 8 Housing. Moreover, even Medicaid disability benefits in Indiana are more difficult to obtain than in 48 other states, resulting in a disproportionately high number of chronically and seriously ill Indiana residents without any form of health care coverage.

Similarly, services and funding opportunities available for children who are seriously emotionally disturbed or who are considered to be at risk of abuse, neglect, delinquency, developmental delay, developmental disability or academic failure in Indiana are not available or managed consistently in each of Indiana's 92 counties. As with many of Indiana's long-term care services for adults, children are often removed from their home environment to receive costly institutional care, even though there are service funds available for treating children in the community. In contrast,

Indiana has, in recent years, enjoyed national recognition for its leadership in enrolling children into the children's health insurance program (Hoosier Healthwise), its home visitation services (Healthy Families) and its early intervention services (First Steps). Each of these services promotes healthy child development, preventive or early intervention strategies to prevent long-term care of out-of-home placements and provision of services in the community. This recognition and success have not been as evident in maximizing federal funding streams that would expand services in a cost effective manner to Hoosier children. The most notable of these are the Medicaid Rehabilitation Option and the Early and Periodic Diagnosis, Screening and Treatment components of the Medicaid program. In each instance, under-utilization of these services is noted even though several areas of the state do in fact utilize them. These federal funds are available but have not been pursued consistently by the State that could further promote community care services for at-risk children.

To increase the momentum for expanding community capacity and consumer choice, the Indiana Family and Social Services Administration, in an unprecedented effort, has teamed up with the U.S. Department of Health and Human Services to pursue innovation and lasting change. Three federal grants have been sought, and subsequently awarded, to assist Indiana in once-and-for-all overcoming the long-standing barriers that have made reform so elusive. At the lead in this effort, is the appointment by Governor O'Bannon of a bi-partisan, broad-based Commission, representing experts in fields that have never before been convened, to direct and coordinate the elements of long-term care in Indiana that have long been disconnected.

The Commission's work is intended to complement, and not duplicate, the valuable work already accomplished by so many others, such as the Senate Bill 317 Commission, the State-Operated Facilities Council, and the Indiana Family and Social Services Administration's Long-Term Care Task Force. Specifically, the Commission's work assignments focus on the "next steps" of building community capacity, eliminating barriers, and developing partnerships and systems that will support consumer choice. Their time-lines are short, and their assignments are daunting. Nevertheless, it is the belief and hope of many that the leadership of the Commission will create the impetus that is needed to finally tip the scales away from traditional modes of care and toward more responsive, consumer-driven, outcomes-oriented community care.

1.1 Background

The policy issues related to "long-term care" in Indiana cannot be fully understood without providing a definition of the term. And while each state and program describes long-term care somewhat differently, all typically share the same common elements. One of the more comprehensive definitions² is as follows:

"...a broad range of help with daily activities that chronically disabled individuals need for a prolonged period of time. These primarily low-tech services are designed to minimize, rehabilitate, or compensate for loss of independent physical or mental functioning. The services include assistance with basic activities of daily living (ADLs), such as bathing, dressing, eating, or other personal care. Services may also help with instrumental activities of daily living (IADLs), including household chores like meal preparation and cleaning; life management such as shopping, money management, and medication management; and transportation. The services include hands-on and standby or supervisory human assistance; assistive devices such as canes and walkers; and technology such as computerized medication reminders and emergency alert systems that warn family members and others when an elder with a disability fails to respond. They

also include home modifications like building ramps and the installation of grab bars and door handles that are easy to use.”

Persons who utilize long-term care services (regardless of funding source) include: the frail elderly; adults and children with physical disabilities; adults and children with developmental disabilities; adults and children with mental illness; and children and their families who are at risk of involvement in the child protective system, the juvenile justice system, or through academic failure in the education system.

Given the scope, variation, and funding source among long-term care services, it is difficult to estimate total expenditures for all services in Indiana. Indiana Medicaid expenditures alone for long-term care services totaled \$1.81 billion in state fiscal year 2000³. Of that, approximately \$773 million was spent on nursing home care, \$289 million on institutional care for persons with developmental disabilities, and only \$101 million on home and community-based services (waiver) care. Another \$38 million was spent by Indiana’s CHOICE Program⁴ to help people remain in the community. Perhaps more revealing are the number of Medicaid recipients served by setting, namely 46,200 in nursing homes, 5,759 in intermediate care facilities for the developmentally disabled (state operated facility, large private facilities, and small group homes), and only 5,089 receiving community services through the Medicaid waiver program.

The payment of services for abused, neglected, and delinquent children is paid through the 92 county family and children’s funds, the revenue source of which is the county property tax. Due to significant local outcry because of the runaway costs of these funds throughout the state in the early 1990s, aggressive action was taken to constrain the growth of the local property tax rates. That provided an impetus for developing family focused, community based services, prevention programming and increasing federal reimbursement through the foster care placement programs. In state fiscal year 2000 over \$27.5 million was expended in the Healthy Families home visitation program. To complement this very positive and beneficial effort to prevent abuse, neglect, and delinquency, the First Steps program expended over \$42.5 million in state fiscal year 2000 to decrease, ameliorate or early intervene when risk factors known to impact developmental delays or disabilities are identified in children ages 0-2. These efforts, while focused in the right direction, must be considered in the perspective of over \$160 million spent in calendar year 2000 on private institutional placements for abused, neglected, and delinquent children, the amount of which does not include costs for children in state-operated facilities, correctional facilities or foster care. Foster care in the community for these children approximated almost \$75 million in state fiscal year 2000, while in home services for children in the child protective system, the juvenile justice system or who were at-risk of entering those systems approximated only \$45 million. Clearly the direction is correct, but the effort is lagging behind the rest of the country at an expense to both the child and the taxpayer. These figures do not include mental health services either at the community or state operated facility level.

Since the early 1980’s, the federal Centers for Medicare and Medicaid Services⁵ have allowed states to use Medicaid funding to creatively design community-based programs that provide real alternatives to traditional forms of institutional care, such as nursing home, group home, intermediate care facility for the mentally retarded, and state operated facilities (all of these are typically defined as “institutional care” for purposes of the Medicaid Program). Many other states have embraced this flexibility wholeheartedly, having successfully shifted the long-term care service balance for their residents to one that favors more desirable and less-costly care in one’s own home or other community setting over traditional and less-desirable institutional settings.

Across the country, consumer frustration with states' unwillingness, inability, and/or slow progress to embrace and develop viable and available community service options for its residents has been mounting in recent years. This frustration is evidenced by an increasing amount of litigation, which culminated in a key disability rights decision, *Olmstead v. L.C.*, issued on June 22, 1999 by the United States Supreme Court. A brief summary offered by the Center for Health Care Strategies, Inc.⁶ is provided below:

"The lawsuit, brought against the State of Georgia, questioned the state's continued institutionalization of two disabled individuals after physicians had determined that they were ready to return to the community. The Supreme Court described Georgia's action as "unjustified isolation," and determined that the state had violated these individuals' rights under the Americans with Disabilities Act (ADA).

The Court explained that unjustified isolation was a form of discrimination. It reflected two judgements: First, institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life...Second, confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.

The Supreme Court was careful to say that the responsibility of states to provide health care in the community was "not boundless." States were not required to close institutions nor were they to use homeless shelters as community placements. Without imposing specific requirements, the Court said that if "...the state were to demonstrate that it had a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the state's endeavors to keep its institutions fully populated, the reasonable modifications standard [of the ADA] would be met." The Court specified that the state must provide community placement and services without displacing others on a waiting list for similar benefits and without unduly burdening the state's resources.

Although the Olmstead decision confirmed the ADA's community integration mandate, the words "housing" or "supportive housing" do not appear in the decision. Instead, the Supreme Court used terms such as "community placements" and "less restrictive settings." Nonetheless, the Olmstead decision could have a profound impact on future state policies and approaches to provide community-based housing and support services for people with significant disabilities. As a result of the Olmstead decision, thousands of people currently living in "more restrictive settings" such as public institutions and nursing homes must be offered housing and community-based supports that are consistent with the integration mandate of the ADA."

As described above, the *Olmstead* decision was a landmark for guiding the delivery of publicly-funded long-term care services, thereby further impressing upon states the need to respond to the decision quickly and decisively.

1.2 The Indiana Family and Social Services Administration

Before and since the time that the *Olmstead* decision was rendered, the Indiana Family and Social Services Administration has engaged in a number of initiatives specifically targeted to increase community care options for individuals who depend upon public assistance for their services. These include, but are not limited to:

- ◆ *The Senate Bill 317 Task Force* – Appointed by Governor O’Bannon in 1997, this group was charged with developing a comprehensive plan for services for people with developmental disabilities, while assisting the Indiana Family and Social Services Administration in the simultaneous closure of two state-operated facilities.
- ◆ *The Governor’s Council on State-Operated Care Facilities* – Created in 1999 in response to on-going concerns about the future of the nine (9) remaining state-operated care facilities for persons with developmental disabilities, Governor O’Bannon appointed a special council to develop a long-range plan to ensure the provision of high quality, cost-effective care in the nine facilities.
- ◆ *Long-Term Care Task Force* – In 2000, Governor O’Bannon appointed a task force to evaluate a number of long-term care issues and to oversee the development of the Medicaid waiver application for assisted living and adult foster care that was mandated by House Enrolled Act 1197.
- ◆ *House Enrolled Act 1767 Continuum of Care for the Elderly and Disabled* – Passed in 2001, this Act mandated the Indiana Family and Social Services Administration to develop a plan that would ensure that services provided under its programs match the needs of the individuals receiving the services. Additionally, it calls upon the agency to file a preliminary and final report.
- ◆ *House Enrolled Act 1950 Medicaid Buy-In* – Also passed in 2001, this Act provides for an expansion of the Medicaid disability program to include certain working individuals with disabilities as authorized by the federal Ticket to Work and Work Incentives Improvement Act.

The Indiana Family and Social Services Administration has initiated and engaged in numerous other initiatives that have led to improved health outcomes and quality of life for many of Indiana’s residents who depend upon public assistance for their health care and social needs. And while limited by serious budget constraints in recent years, the agency continues to actively and aggressively pursue program and system reforms that will collectively and significantly improve the long-term care service delivery system in Indiana.

Evidence of this commitment to change is the agency’s diligent pursuit and subsequent award of three grants offered by the Centers for Medicare and Medicaid Services within the U.S. Department of Health and Human Services.

The three grants and a brief description of each are as follows:

- *Real Systems Change Grant.* The purpose of this grant is to: establish a Commission that will provide a constant forum for interaction with consumers of long-term care services and their advocates; identify best practices and barriers to community integration and consumer control; provide oversight and monitoring; assist in the implementation of a series of mini-grants to local communities; and make further recommendations for policy and funding actions.
- *Nursing Home Transitions Grant.* The purpose of this grant is to: develop models for diversion from and transition and of nursing home residents back into the community; provide training, education, and outreach; collaborate with nursing home associations, housing partners, assisted living facilities, and community stakeholders; develop a team to design and facilitate the transition process; identify and select candidates to be transitioned and/or diverted; and evaluate and prepare reports.

- *Community Personal Assistance Services and Supports (CPASS) Grant.* The purpose of this grant is to: provide outreach and information about consumer-directed care services; develop a consumer-directed personal assistance services model and the supporting infrastructure; establish a fiscal intermediary structure for the attendant care workers; provide enhanced training; develop quality assurance, conflict resolution, and emergency assistance protocols; and develop a system for outcomes-based reporting.

1.3 Governor's Commission on Home and Community-Based Services

On July 30, 2002, Governor Frank O'Bannon made the announcement that he had formed the Governor's Commission on Home and Community-Based Care. It is funded primarily by the Real Systems Change Grant, but also receives funds from the Nursing Home Transitions and Community Personal Assistance Services and Supports grants for its role in coordinating all three initiatives; it uses no state funds.

The Commission is both broad-based and bi-partisan. It has twenty-one members, representing consumers, advocates, clergy, legislators, government, business, the service industry, public policy, education, and the medical and legal professions. Each member was selected for his/her unique perspective on the many issues and obstacles facing Indiana's frail seniors, children and adults with disabilities, persons with mental illness, and children and families who are considered to be at-risk. A complete list of Commission members can be found in the Appendix.

The purpose of the Commission is to develop short and long-term strategies to create or expand community options for persons at risk of being institutionalized, or for those currently in a nursing home or other institutional setting within Indiana's long-term care service delivery system. Its specific functions include: identification of the policy issues surrounding institutionalization; compilation of key statistics and other resource materials; identification of successful and innovative programs that break traditional housing and service barriers; solicitation of consumer perspective; and development of funding and policy strategies. It is scheduled to meet monthly for a twelve to eighteen month period, and produce both an interim and a final report for the Governor.

As of the time that this report was written, the Commission has met six times and has scheduled at least six more meetings through and including the month of June 2003.

In order to assist in accomplishing these many assignments, the Commission has convened five special task forces and a Consumer Advisory Committee specifically designed to research and evaluate the relevant policy issues, advise the Commission, and increase the scope and substance of Hoosier participation to ensure that all with interest are involved in formulating the solutions needed to break new ground in Indiana. Each of the five task forces are devoted to specific policy areas of concern, while the committee is comprised solely of consumers and advocates with the express purpose of evaluating all task force work and advising the Commission. A complete listing of the task forces and the Consumer Advisory Committee, their specific purpose and function, and their membership can be found in the Appendix.

1.4 Mission Statement and Guiding Principles

Beginning at their first meeting, the Commission realized the importance of focusing on the assignments expressly presented them by Governor O'Bannon, and building upon and not duplicating the significant body of work already produced by numerous, preceding task forces and commissions. Moreover, they quickly came to appreciate the existing skepticism of many regarding the Commission and whether their work should, in fact, provoke lasting change and improvement in policy areas that have been frustratingly slow to evolve in Indiana.

In direct response to these challenges, the Commission resolved to develop recommendations that would transcend political interests and time-lines and that would complement (not duplicate) the continuing work of others, thereby creating an impetus for change that would be difficult to restrain.

The Commission's commitment is memorialized in a mission statement (Preamble) and five guiding principles, which are specifically intended to assist them in establishing clear and meaningful boundaries and direction for their work.

The Commission on Home and Community-Based Services exists to pursue common and aggressive actions that will facilitate immediate and lasting change in long-term care services in Indiana. The Commission's work is targeted to persons who already are, or who may sometime in the future depend upon long-term care services. The Commission will develop these recommended actions based upon a public policy that makes sense, is financially accountable, and promotes personal choice by the persons receiving or at risk of receiving these services. The Commission will build upon the good work already accomplished by other commissions and groups and will be guided by activities and implementation strategies that improve the lives of people currently affected by these services. Each recommended action is intended to help overcome the already well-known systemic barriers, current policies and procedures, and organizational practices that are obstacles to change.

Guiding Principle 1: Authority and Power of the Commission. The Commission recognizes that additional statutory or executive authority may be needed to implement the recommended activities and strategies that can improve service delivery for those persons who require or are at risk of requiring long-term care services. However, the Commission also recognizes that true power comes in the ability to facilitate problem-solving in a meaningful and common sense manner that transcends political, financial, and bureaucratic concerns. The Commission will articulate each strategy and recommended action step in a clear and concise manner that also identifies the consequences for refusing to enact the recommended action.

Guiding Principle 2: Accountability. The Commission will base its decisions upon information that is irrefutable so that a consensus can be achieved to bring about the systems change that is desired and that meets legal, financial, programmatic, and human expectations.

Clear, measurable objectives will be identified, and timetables will be established that will form the basis of a three (3) to five (5) year action phase that is reasonable, realistic, and attainable. Any additional action phases will be a natural consequence of this initial phase, thereby reducing the likelihood of later modifying a longer-term strategy. The Commission understands the reality of budget constraints and will advocate current resource maximization that includes creative state plan amendments and waiver submissions prior to the development of any budgetary request.

Guiding Principle 3: Personal Choice. The Commission will identify strategies that promote the development of sufficient and quality care alternatives necessary to ensure true personal choice in all service settings.

Guiding Principle 4: Collaboration. Collaboration must exist throughout all levels of state and community agencies and organizations involved in services for long-term care. The Commission will serve as a “best practices and innovation” forum to ensure accurate information and education so training and organization culture changes can promote meaningful and real systems change. The Commission recognizes the importance and value of staff in each agency and organization involved in long-term care service delivery and endorses systems changes that allow staff to assist long-term care consumers to best meet their needs according to personal preferences.

Guiding Principle 5: Prevention and Early Intervention. The Commission is committed to the expansion of prevention and early intervention services that can decrease the incidence of causative factors that lead to a person’s need for long-term care services.

1.5 Mini-Grants

As part of the Real Systems Change Grant that is funded by the Centers for Medicare and Medicaid Services, the Commission is working with the Indiana Family and Social Services Administration to develop and award a number of mini-grants. These mini-grants are designed to create community partnerships, provide incentives for public/private partnerships, and serve to encourage innovation at the community level between community stakeholders.

The mini-grants are directed to the three major goals of the Commission:

- To develop community capacity in the areas of community living arrangements, affordable housing, transportation, supported employment, and caregiver support.
- To develop systems that support consumer choice and consumer-directed care.
- To develop innovative systems that identify and propose solutions to eliminate barriers to service.

The Commission and the Indiana Family and Social Services Administration will also accept proposals that address other areas that propose, support, and validate enduring system changes. Grants will be considered if they foster collaboration among community partnerships. There will be more smaller-sized grants given, rather than select larger grants to a few communities. Innovation will be favored over traditional, and initiating new capacities will be favored over expanding existing capacities. The focus will be on maximizing and leveraging the funds by working with matching and other funding sources in the local communities.

There will be two rounds of grant solicitations.

The schedule for the first round of grants will be:

Solicitation of proposals	December 2 – December 13, 2002
Proposals due to FSSA	January 15, 2003
Proposals evaluated and approved	January 15 – February 14, 2003
Notice of awards	February 15, 2003

The schedule for the second round of grants will be:

Solicitation of proposals	March 3 – March 14, 2003
Proposals due to FSSA	April 15, 2003
Proposals evaluated and approved	April 15 – May 15, 2003
Notice of awards	May 15, 2003

1.6 Fact Book

In order to respond to the assignment to compile key statistics and other resource materials, the Commission is directing the development of a housing and long-term care services fact book. The fact book is specifically intended to fill a long-standing information gap in Indiana by collecting a comprehensive body of Indiana-specific and national data that can assist consumers, providers, and researchers. Existing information is scattered, outdated, often difficult to obtain or understand, and sometimes contradictory. As a result, well-founded and successful policymaking becomes considerably more challenging.

Once complete, the fact book will comprehensively describe the characteristics and service needs of Indiana Hoosiers who are frail and elderly, physically and/or developmentally disabled, experiencing mental illness, or children/families at risk.

Further, the Commission will identify statistical information and/or data questions that are needed for policy-making but that may not be compiled, up-to-date, or readily available. For this category of information, it is the Commission's intent to present the policy/data questions to the Indiana University School of Public and Environmental Affairs and any other research entity that may have an interest in researching and compiling the needed information and statistics.

1.7 Commission Web Site and Reference Information

The Indiana Family and Social Services Administration has developed and maintains a web site specifically to present and report on the activities of the Governor's Commission on Home and Community-Based Services.

This web site is: <http://www.in.gov/fssa/community/> and includes viewing and downloading capability for this report; meeting schedules, agenda and minutes; task force meetings and other information; information on the mini-grant solicitation; and other resource and informational material.

The Commission has also begun a reference and website list of relevant literature and other documents that have been published on one or more of the long-term care topics being researched and studied. This list can be found in the Appendix.

Chapter 2: Sixteen (16) Interim Recommendations for Immediate Implementation

2.1 Introduction

Each of the five (5) task forces were developed and convened soon after the Commission held its first meeting on August 8, 2002. Each was given a separate series of assignments (See the Appendix for the purpose, function, and membership of each) and asked to report back to the Commission regularly with status updates that included findings and recommendations.

Similarly, the Consumer Advisory Committee was also developed and convened soon after the Commission's first meeting. Its purpose is to evaluate the work completed by the task forces and advise them and the Commission accordingly.

By the time that the Commission held its third meeting on September 26, 2002, concerns were expressed that the original assignments and time-lines established for both the Commission and its task forces may not be responsive enough to the urgency of many of the system problems. In addition, there was agreement that the opportunities for policy change presented by the upcoming legislative session must be actively pursued. As a result, the Commission deemed it necessary to deviate from its original workplan and instead refocus the task forces on identifying most/all of the long-term care service delivery barriers and to develop comprehensive recommendations in response. Each recommendation that was subsequently developed was then assigned to one of three categories: those that should be implemented quickly and with little or no fiscal impact or regulatory obstacles; those that should be implemented quickly but that are accompanied by a fiscal impact and/or regulatory requirements; and those that are more complex, costly or otherwise difficult that will take more time to develop and implement.

Despite extremely challenging time-lines, the task forces were able to develop an initial list of recommendations for each of the three categories. Time constraints required them, the Consumer Advisory Committee, and the Commission to focus their attentions on the recommendations in the first category, those that should be implemented quickly and with little or no fiscal impact or regulatory obstacles. Therefore, this first list of sixteen (16) recommendations is highlighted within this report. Some include very specific and detailed steps to be taken, while others describe the necessary action steps somewhat more generally.

The recommendations included in the other two categories are also briefly presented within this report for reference, but are not yet fully developed. The task forces, the Consumer Advisory Committee, and the Commission will be focusing on them throughout the next several months and comprehensively presenting them in the final report.

It also quickly became clear that many of the barriers identified in the task forces were common to all target populations. Therefore, each barrier/recommendation was grouped according to one or more "themes." These themes include: eligibility; streamlining or maximizing funding; developing provider incentives to increase capacity; consumer education; and consumer choice.

All sixteen of the immediate recommendations directly respond to system barriers and are absolutely critical to developing the longer-term recommendations that are presented in Chapter 3. Moreover, all are believed to be simple to implement and with little or no cost. The

Commission did not prioritize them but instead includes them collectively in this Interim Report as recommended actions that should be immediately and aggressively pursued.

The Commission also recognizes that there are some system barriers that are perhaps outside the control or purview of the Governor and must be resolved at a community level. An example of one that merits special attention is a significant barrier to affordable housing that has been discussed at length in both the Housing Task Force and the Consumer Advisory Committee regarding public housing programs. Specifically, elderly individuals and individuals with disabilities often do not have real choice in affordable housing and support services for various reasons including, but not limited to, discriminatory practices, regulatory issues, resources, availability of desired housing options, or lack of desirable options. Resolution of this significant barrier requires publicly-funded housing programs to embrace certain funding and operational principles. These should include, but not be limited to:

- The ability of consumers to own the property or have leases in their own name;
- Availability of support services that are coordinated between housing and service providers to assist individuals to remain in their own home;
- To the extent possible, agencies providing affordable housing shall assure that consumers have choice in the provision of support services;
- Integration of affordable housing into the community;
- Availability of safe, clean and affordable housing targeted to individuals with the lowest incomes;
- Availability of voluntary, 24 hours a day/7 days a week community-based support services; and
- Consumer choice.

While this specific housing problem is not highlighted in this report by a specific recommendation, the Commission recommends that this problem should be delegated to the Indiana Low Income Housing Trust Fund Board described in Recommendation 4 for further analysis.

The sixteen (16) immediate recommendations developed by the Commission are presented below. Each presents a summary of the barrier or problem, which is then followed by the proposed solution or recommendation.

2.2 Eligibility

Of the sixteen (16) immediate recommendations the Commission has developed, two (2) are related to program eligibility and can be resolved quickly and with little or no fiscal impact or regulatory changes. Each is described as follows.

Problem: According to federal regulation, Indiana's Medicaid Home and Community Based Services Waiver for the Aged and Disabled is specifically intended to target persons in need of nursing home care⁷. Therefore, it utilizes the same medical eligibility criteria as is used for nursing home placement. In contrast, however, Indiana's Waiver applies financial eligibility criteria to married couples that are considerably more strict. Specifically, the spouse of a person who enters a nursing home is allowed to maintain up to about \$89,000 in assets, while the spouse of a person who prefers to receive services in their own home may only maintain combined assets of \$2,250. In short, this policy penalizes persons who choose to marry and encourages married people to divorce. The practical effect of this policy is that many of Indiana's married couples typically decide either to go without care, or instead must accept the services available in a nursing home. While the couple prefers to remain together in their own home to receive care, that choice is denied because spousal impoverishment protections are not also included in the Waiver.

Recommendation 1: Make financial eligibility for the Medicaid Aged and Disabled Waiver (and any other applicable waiver) the same as for Medicaid-funded nursing home placement by implementing spousal impoverishment protections. This policy provision has already been implemented into Indiana's Medicaid Assisted Living Waiver Program for Persons Who Are Aged and Disabled and to most other aged and disabled waiver programs throughout the country.

Target Population. Those who would be affected by this change are married persons who are frail and elderly and/or disabled, and who meet nursing home eligibility criteria, including: adults age 65 and over; physically disabled individuals of any age; and persons with developmental disabilities who have overriding medical needs.

Policy Outcomes. Implementation of this recommendation will remove the long-standing barrier that currently prevents persons who are elderly or disabled who need nursing home services from choosing where and by whom they receive services. Specifically, it requires the same financial criteria to be established for both service settings, thereby allowing married persons the choice of receiving services in their own homes or other community setting and at less cost (this is a federal requirement). Further, it is anticipated that persons who receive care in their homes will remain independent longer and may avoid nursing home placement altogether. Finally, it is important to note that the adoption of this policy change will remove a significant and long-standing obstacle that has created an institutional bias for elderly and disabled persons and impeded community transition.

System Barriers. Successful implementation of this recommendation will require extensive training and educational outreach among county offices of family and children and the sixteen area agencies on aging. Other administrative costs should be minimal, since the financial eligibility criteria used to determine nursing home eligibility is already in place and will now govern the waiver eligibility determination process.

Responsible Agencies and Action Steps. The Office of Medicaid Policy and Planning, the Division of Family and Children, and the Division of Disability, Aging and Rehabilitation Services within the Indiana Family and Social Services Administration are responsible for pursuing and implementing this change. They have already approved this policy change and are now awaiting approval from the Centers for Medicare and Medicaid Services. Action steps include responding to any questions or concerns raised by the Centers for Medicare and Medicaid

Services; developing the written policy; training staff involved with eligibility determinations; and implementing the new provision.

Fiscal Impact. Since the waiver program limits the number of people who can be served each year, there is minimal fiscal impact associated with implementing this policy change. Any administrative costs will consist of training and educational outreach. The practical effect of this policy change can, however, be expected to grow the number of people waiting to receive services.

Targeted Completion Date. This policy change should be initiated immediately, with an implementation date of February 1, 2003 or the date that approval from the Centers for Medicare and Medicaid Services is received.

Problem: As stated previously, federal regulation mandates that Indiana's Medicaid Home and Community Based Services Waiver for the Aged and Disabled specifically target persons who are in need of nursing home care. Similar to Indiana's spousal impoverishment protection policy, there is an inequity between the monthly income standard for the Aged and Disabled Waiver (and some of Indiana's other Medicaid Waiver Programs) and the monthly income standard established for both nursing home services and two of Indiana Medicaid's other waivers. Specifically, the Aged and Disabled Waiver monthly income standard allows an individual to have no more than the monthly Supplemental Security Income (SSI) amount of \$545 of living income. This means that if the individual's income exceeds \$545 in any given month, (s)he is not eligible for services. The individual must spend down his/her income to become eligible. In contrast, that same individual can be eligible for services in a nursing home by paying all of his/her income to the nursing home as patient liability (less a monthly \$52 personal needs allowance). By raising the income standard to the federally-allowed limit of 300% SSI (i.e. \$1,635) monthly, an individual is permitted to keep more of his/her income and still be eligible for services. This current, very stringent income standard established for the Medicaid Aged and Disabled Waiver denies many persons who are frail and elderly or physically disabled from receiving necessary services in their own homes.

The 300% SSI standard has already been adopted for consumers who receive services through the Medicaid Developmental Disabilities and Support Services Waiver programs.

Recommendation 2: Raise the monthly income eligibility standard for the Medicaid Aged and Disabled waiver (and all other applicable waivers) to 300% of the Supplemental Security Income amount.

Target Population. Those who would be affected by this change are persons who are frail and elderly and/or disabled, and who meet nursing home eligibility criteria, including: adults age 65 and over; physically disabled individuals of any age; and persons with developmental disabilities who have overriding medical needs.

Policy Outcomes. The implementation of this recommendation will establish policy consistency and equality between all Medicaid Waiver programs and Medicaid-funded nursing home services. It will help to eliminate institutional bias and effectively eliminates Medicaid spend down for most individuals already receiving services through the Medicaid Aged and Disabled Waiver. It will establish a balance in Indiana's long-term care service delivery system by allowing all

nursing home eligible persons the choice of receiving services in a nursing home or in their own homes or other community setting. It is also important to note that this policy change has already been made to two of Indiana's Medicaid waivers that serve persons with developmental disabilities. Finally, the adoption of this policy change will remove a significant and long-standing barrier in providing and expanding community services for persons who are frail and elderly or physically disabled.

System Barriers. Since the calculation of Medicaid spend down will be affected for those persons with incomes higher than \$545 per month, a fiscal impact analysis must be completed in order to determine the administrative and system effects and the costs and time-lines associated with implementation of this recommendation.

Responsible Agencies and Action Steps. The Office of Medicaid Policy and Planning, the Division of Family and Children, and the Division of Disability, Aging and Rehabilitation Services within the Indiana Family and Social Services Administration are responsible for pursuing and implementing this change. The action steps include: developing the written policy; calculating a comprehensive and accurate fiscal impact; identifying any state match funds that may be needed; training staff involved with eligibility determinations; and submitting that policy change in written Medicaid amendment to the Aged and Disabled waiver to the Centers for Medicare and Medicaid Services.

Fiscal Impact. Federal regulation specifies that the average per capita cost to Medicaid of the Waiver Program must be no more than the average per capita cost⁸ to Medicaid of persons served in the comparable institutional setting (nursing home). Recognizing this, an accurate and reliable fiscal impact must address a number of cost and program factors specific to: persons already on the Aged and Disabled Waiver; persons in nursing homes; and persons in the community whose future choice of care is expected to be affected by this policy change. Specifically, the fiscal impact analysis must include an evaluation of the following factors:

- Average per-person Medicaid and other state-funded (i.e. CHOICE) costs for all Aged and Disabled Waiver consumers, including the distribution of costs (ranging from high to low);
- Average per-person Medicaid and other state-funded (i.e. CHOICE) costs for nursing home consumers, including the distribution of costs and the effect of CMI scores on reimbursement;
- Aggregate Aged and Disabled Waiver and nursing home costs
- Medicaid spenddown and patient liability; and
- Total funded waiver costs, including both used and unused waiver slots.

It is recognized that there will be some immediate costs associated with the implementation of this policy change, however, it is also expected that there will be off-setting cost savings, both immediate and long-term that will be achieved. Therefore, the analysis must also include a detailed evaluation of the immediate and on-going cost effects of the diversion of more people from nursing home care that this policy change is expected to provoke. Specifically, a full description and evaluation of anticipated cost savings must be included.

Finally, this analysis must include a report of the number and names of states that already utilize the 300% Supplemental Security Income policy option for their aged and disabled (or equivalent) waiver, as well as other states' fiscal considerations and program experience relevant to the adoption of the federally-allowed 300% Supplemental Security Income financial eligibility criterion.

Targeted Completion Date. A comprehensive fiscal impact analysis should be completed by the end of February 2003.

2.3 Streamlining or Maximizing Funding

The Commission has developed six (6) recommendations that are related to streamlining of processes or maximization of funding and that can be resolved quickly and with little or no fiscal impact or regulatory requirements. Each is described as follows.

Problem: The 2000 U.S. Congress amended the definition of “homebound” for Medicare home health beneficiaries to allow them to attend licensed or accredited adult day services. Indiana Medicare beneficiaries are being denied adult day services since Indiana does not require adult day services to be licensed and since no licensing substitute has been requested or presented.

Recommendation 3: The Indiana Family and Social Services Administration should request approval from the Centers for Medicare and Medicaid Services to allow the certification and quality monitoring process that is currently in place for adult day services to serve as a substitute for state licensure. This will allow a beneficiary to receive Medicare-funded home care and also attend adult day services (not funded by Medicare) without risking the beneficiary’s Medicare homebound status.

Target Population. Those persons who would be affected by this change are all Indiana residents who are elderly and/or disabled Medicare beneficiaries and who wish to participate in publicly-funded adult day care services and their families or other private caregivers.

Policy Outcomes. Implementation of this change will expand the service options available to persons who are frail and elderly or persons who are disabled, and to the families and other people who care for them. This change will allow families to continue to be employed while still caring for a disabled person or frail elderly in their home or another community setting, thereby enhancing the likelihood that the consumers will be able to “age in place.” And finally, it will improve the socialization and quality of life of the frail elderly and persons who are disabled, and provide much-needed respite and/or employment relief for their caregivers.

System Barriers. There are no administrative or system barriers associated with this policy change.

Responsible Agencies and Action Steps. The Office of Medicaid Policy and Planning and the Bureau of Aging and In-Home Services within the Indiana Family and Social Services Administration are responsible for pursuing and implementing this change. The action steps include composing and submitting a letter of request to the Centers for Medicare and Medicaid Services, responding to any written follow-up that may be required, and re-training staff who assist consumers with Medicare coverage issues and identification of service providers in Indiana.

Fiscal Impact. There is no state fiscal impact associated with this change.

Targeted Completion Date. The written letter of request should be submitted to the Centers for Medicare and Medicaid Services by January 15, 2003. The effective date will be determined by the date when written approval from the Centers for Medicare and Medicaid Services is received.

Problem: The 1988 Indiana General Assembly established the Indiana Low Income Housing Trust Fund Board⁹ in order to develop a permanent, non-renewable revenue source that will be utilized to support the financing of affordable, low-income housing. This Board was developed but never fulfilled its original charge.

Recommendation 4: The Governor should re-appoint the Indiana Low Income Housing Trust Fund Board to fulfill the original charge presented in 1988 to make recommendations regarding long-term funding sources to capitalize the housing trust fund and to serve as a focal point for creating affordable housing opportunities state-wide to help low-income and persons at risk remain in and/or return to the community.

Target Population. Those who would be affected by this change are all persons and families with low-income, especially those who are at risk, including the frail elderly, persons who are physically and/or developmentally disabled, and persons with mental illness.

Policy Outcomes. Re-establishment and re-dedication of this Board will facilitate a much-needed collaboration among housing and community program and services administrators, providers and consumers to explore public-private partnerships and grant funding needed to develop more affordable housing options for low-income persons in need of services. The Board will further assist the State in formalizing the critical link between availability of safe, affordable, and accessible housing with the community services needed to promote consumer choice and quality of life.

System Barriers. Staff support is needed to administer the Board. Also, clear lines of authority and responsibility will need to be established to ensure that the Board works collaboratively and efficiently to develop viable, significant, and lasting changes.

Responsible Agencies and Action Steps. The Governor's Office, in collaboration with the Indiana Housing Finance Authority (IHFA), is responsible for re-establishing the Board. Action steps include: appointing the board members; assigning priority to its function; issuing a written list of directive(s) for the board members, including expected outcomes with time-lines; developing a progress report expectation; and issuing one or more press releases. It is suggested that a Real Systems Change mini-grant be pursued to assist with funding staff/consultant support for board development.

Fiscal impact. The long-term fiscal impact relative to board expenses needs to be further examined (refer to Indiana Administrative Code 5-20-4 for explanation of board expenses).

Targeted Completion Date. The Indiana Low Income Housing Trust Fund Board should be appointed before April 1, 2003. Board recommendations should be submitted to the Governor by October 1, 2003.

Problem: Indiana currently has few comprehensive, evidence-based treatment options for serious emotionally disturbed children who are eligible for admission to a state hospital. As a result, children are often removed from their familiar environment and institutionalized for treatment at significant expense and with less-than optimal outcomes.

Recommendation 5: Develop, submit, and implement a Medicaid Home and Community Based Services Waiver for children with serious emotional disturbance. This waiver would allow evidence-based community treatment options for children with serious emotional disturbances that would include: wraparound facilitation; respite; flex fund; psycho-educational/behavioral training for families; independent living services; mentoring; and treatment foster care.

Target Population. Those who would be affected by this change are children with serious emotional disturbance and their families.

Policy Outcomes. The cost for community-based services will be lower than the cost of institutionalization, allowing more children to be served for less. Additionally, expanding evidence-based community treatment modalities allows children to remain in a familiar setting and generally ensures better outcomes.

System Barriers. The Indiana Family and Social Services Administration's Division of Mental Health and Addictions must work with its sister agencies, the Divisions of Family and Children and the Division of Disabilities, Aging and Rehabilitative Services, and the Indiana Department of Education, and all local counterparts to ensure that providers and agency staff understand the waivers and have the necessary internal administrative processes in place to make them effective. A process must be established that will identify local, un-leveraged county and state funds that can be used to pay for the state share of the Medicaid services. Other processes must include: the establishment of a clear and consistent policy statement about the use of the waiver; development of eligibility and enrollment procedures; refinement of the county accounting system (CAS) so matching funds can be identified and tracked; training of staff in the management of the waivers; and development of evaluation and monitoring reports for planning purposes. In order to ensure community-level collaboration of local agencies, a forum must be convened to provide service agencies an opportunity to collaborate with each other so they all can work with families to promote the most effective wraparound services for the child. Similarly a policy or process must be established at the state level to mediate funding and policy disagreements between the divisions of the Indiana Family and Social Services Administration. The agency must develop or refine an effective monitoring system to assist in local implementation and to serve as a technical assistance resource for problem-solving, community capacity building and strategies that promote local collaboration.

Responsible Agencies and Action Steps. The Division of Mental Health and Addictions should serve as the lead agency for developing and implementing this waiver. It will need to develop a work team that includes representatives of the: Division of Family and Children; Department of Corrections; Department of Education; Division of Disability, Aging and Rehabilitation Services Medicaid waiver program staff; Office of Medicaid Policy and Planning; IARCCA; Community Mental Health Centers Council; state hospital youth staff; parents and advocates. Action steps will include: developing and staffing the work team; developing program and waiver policy; writing and submitting the waiver; designing a pilot program; identifying match funds that may

be available from other child welfare service's un-leveraged funds; and submission of a State Medicaid Plan amendment.

Fiscal Impact. There should be no short-term fiscal impact associated with implementation of this new Medicaid waiver program since it is expected that state match funds could be made available by the Department of Correction, Department of Education, and the Divisions of Family and Children and Mental Health and Addictions. There will, however, be administrative costs associated with the administration and monitoring of a new Medicaid waiver program. These costs are eligible for 50% federal funding match and may also be covered by the newly-identified match funds. The long-term fiscal impact is expected to create savings to the State or remain revenue-neutral by serving more children in the community at the cost of institutional care.

Targeted Completion Date. The targeted date to submit the Medicaid waiver application to the Centers for Medicare and Medicaid Services is June 1, 2003. A pilot program should be implemented beginning in the Fall of 2003.

Problem: There is inconsistency in the availability of children's mental health services throughout the State. Rural and urban areas of Indiana typically cannot support or provide an appropriate and cost-effective array of services for children. The significant portion of services available for delinquents and abused and neglected children are paid for through Indiana's 92 county family and children's funds. The source of revenue to these funds is the local property tax. In the absence of appropriate and adequate children's services, a natural consequence is the removal of the child from the home and placement of the child in an aggregate living environment often outside the community. Reimbursements for certain placements for Medicaid-eligible children cover the room and board and specific "administrative" costs associated with the placement agency's operation; treatment costs are not, however, reimbursed through the federal reimbursement program for foster care placement. These conditions not only unnecessarily remove more children from their homes, but also represent a failure of local communities to maximize reimbursement opportunities that are available for the services.

Recommendation 6: Expand access to Medicaid Rehabilitation Option funding to include state-licensed, accredited, and/or certified child placement agencies.

Target Population. Those who would be affected by the change are Medicaid-eligible children and families in which an out-of-home placement has been ordered by a Court, and children and their families who have been identified by the Court or any other local community agency that provides services to at-risk children. The definition of "at-risk" refers to children who have been identified as potential victims of abuse or neglect, are considered pre-delinquents or who are having difficulties attending school, or who perform poorly due to emotional or other educational handicaps.

Policy Outcomes. By providing additional federal funding through the Medicaid Rehabilitation Option, more Hoosier families and at-risk children will receive earlier intervention services, increased choice in qualified providers, improved child well-being outcomes, and increased accessibility to services, especially in rural areas.

System Barriers. Expansion of the Medical Rehabilitation Option will allow the inclusion of service providers other than the local community comprehensive mental health centers, which are

currently the only providers that have access to this funding source. The ability to monitor the use of these funds will require upgrade of the county accounting system (CAS) to ensure adequate fiscal accounting and integrity. County Directors of the Family and Social Services Administration's Division of Family and Children will have to understand the manner in which to request and utilize funds for the match and will have to train staff in the availability of this option. These processes can best be served by a clear and direct policy statement about the use of these funds to promote community-based services. Effective monitoring of the use of the funds must be managed at the state agency level, and monitoring reports must be made available to identify the utilization of these funds. At the local level, communities must continue to build service capacity and identify a forum to discuss individual children's cases and the effectiveness of the service providers. Expansion of the Medicaid Rehabilitation Option must be consistent with the goals of a community's Early Intervention Plan. Local purchase of services can be effective only if the solicitation for the services adequately articulates the community's needs as presented in the Early Intervention Plan, and if contractual agreements exist that hold the referring agency and the service provider accountable for positive outcomes for children.

Responsible Agencies and Action Steps. Responsibility for developing and implementing this policy change rests with the Office of Medicaid Policy and Planning, the Division of Family and Children, the Division of Mental Health and Addictions, and the Department of Education (Article 7 funding). Action steps include: developing a clear statement of program policy; informing and educating the child welfare and public assistance staff of the 92 Offices of Family and Children about the importance of these services; implementing necessary computer system changes, both within the financial data systems and the child welfare information system; educating and training providers in conjunction with agency staff, community service systems and consumers; amending and promulgating administrative rule; submitting a Medicaid State Plan Amendment; and possibly refining the policy on the development of local Early Intervention Plans.

Fiscal Impact. Although the fiscal impact is expected to be minimal, there will be administrative cost involved with changing the infrastructure for both the state and providers. Conversely, this change is expected to increase the state/county match amounts for children not covered by the children and families fund and could also reduce the hourly cost of service. Finally, this change will draw down more federal dollars, thereby enabling more children and families to be served at less cost to the State.

Targeted Completion Date. The changes should be implemented during July 2003.

Problem: The State of Indiana received permission from the federal government in 1996 to initiate a pilot program that would allow reimbursement for community-based services provided to children and their families while the child remained in the home. This was a waiver from the federal policy that authorized reimbursement only when a child was removed from the home. The waiver also authorized reimbursement when a child was not Medicaid eligible. To date, the third party evaluation of the waiver has been positive for the communities in which the waiver has been pursued aggressively. There has been however, an inconsistent use of these funds throughout the 92 counties. On a related but different issue, the U.S. Congress passed legislation several years ago that recognized that some children in foster care would never be adopted. Therefore a permanency plan for those children needed to recognize that the child might require an independent living arrangement. Again, this source of funds has not been utilized consistently throughout Indiana's 92 counties. Although these two initiatives promote the use of community-based services for children, they are inconsistently utilized, resulting in a situation where federal dollars are being reverted to the federal government when there is an unmet need in Indiana for services available to at-risk children.

Recommendation 7: The Family and Social Services Administration will need to re-emphasize the original intent of the IV-E waiver to promote the expansion and use of community based services for children in, or at-risk of entering the juvenile justice system or the child protective system and to provide post-adoption services for special needs adoptive children. On-going training should be conducted to assist staff in understanding how the waiver fits within the context of a comprehensive system of care for children and how the waiver program meets the overall policy objectives of the Governor and the agency to expand and utilize community-based services when appropriate. Local directors of the 92 Offices of Family and Children should re-evaluate their original waiver plan to determine if the array of services offered still represents the services most needed in that specific community. Monthly monitoring of the waiver usage should be managed at the state level to ensure maximization of use and the maintenance of budget neutrality. Similarly, the Independent Living funds made available to Indiana by the federal government should be re-assessed to facilitate a child's transition from foster care to independent living arrangements in a safe and coordinated manner. And finally, on-going training should be conducted to promote the use of these funds to foster and expand community services for these children moving to adulthood, with monitoring at the state level to ensure quality services, safety for the children and maximization of funds.

Target Population. Those who would be affected by this policy change are children participating in the Adoption Assistance Program and children age 14 - 21 that are currently on waiting lists for independent living services that target employment, education and affordable housing options.

Policy Outcomes. Both of these initiatives can improve the functioning of the child and the child's family in the community. Children can learn coping mechanisms that promote positive behavior, while parents can learn parenting skills and the techniques that can promote those positive behaviors in their children. This creates greater family stability and the positive outcomes in children that are normally expected, such as school attendance, educational participation and greater accountability in decision-making. For children that must be removed from the home, these services will bring about the same outcomes, while emphasizing the greater decision-making the child must make personally. Children in need of independent living services could be employed, complete their education, and live in safe, affordable housing with the appropriate guidance and mentoring that these services can provide.

System Barriers. The greatest systems barriers will revolve around the change in organizational culture that must exist within the 92 Offices of Family and Children and the provider community. These local community agencies must collaborate as a team to ensure that all basic human needs are met for the children in the independent living program, while ensuring that the mentoring typically provided by parents is arranged through other community resources. The county accounting system (CAS) will have to be upgraded to ensure proper fiscal accountability and integrity, and local, community capacity building will have to be expanded. A public education component must be developed, as well as a willingness to complete the additional administrative processes required by the federal terms and conditions of the waiver or the independent living program. A primer on continuum of care systems and services should be provided to all staff within the state agencies and the provider community, and the Indiana Family and Social Services Administration should assume a leadership role in providing the technical assistance to assist communities in pursuing these systems of care.

Responsible Agency and Action Steps. The Division of Family and Children will be the lead agency responsible for working with the state's technical and coordinating advisor (Ball State University), the Indiana Family and Social Services Administration's Independent Living Steering Committee, and the early intervention teams at the county level. Specific action steps include:

- The Division of Family and Children will need to issue a re-emphasis of the importance of waiver program and how it meets the Governor's commitment to community-based services by February 1, 2003.
- The Division must perform training with the County Directors no later than the February 2003 regional meeting.
- The Division must request the County Directors to re-evaluate their original IV-E waiver plan with their local Juvenile Court Judge by mid-March 2003.
- The Division must actively and timely review monthly utilization reports to monitor the program and to initiate remedial action when necessary.

Fiscal Impact. The fiscal impact is expected to require no increase in state service or program funds, but additional administrative funds may be expended to initiate the training, education, guideline development and financial systems changes that will be necessary. While it is recognized that the use of these two initiatives can reduce costs and expand community services, there will be a fiscal impact administratively to develop or refine the administrative infrastructure needed to manage these initiatives effectively.

Targeted Completion Date. The independent living guidelines should be developed by January 31, 2003, the administrative structure model by April 1, 2003, and IV-E waiver with Adoption Assistance Program children beginning education by March 1, 2003. Additional timelines for the Division of Family and Children are presented in the Action Steps listed above.

Problem: The reimbursement process for transportation providers that participate in Indiana's Medicaid Home and Community Based Services Waiver Programs is cumbersome and confusing. Further, the payment rates are not consistent between traditional Medicaid and the waiver programs. As a result, providers are hesitant to participate.

Recommendation 8: The State should revise, simplify, and make consistent the current waiver process and payment methodology for Medicaid transportation providers.

Target Population. Those who would be affected by this recommendation are persons who are enrolled in Medicaid and the Medicaid waiver programs and who are dependent upon the Medicaid Program for transportation; as well as Medicaid and Medicaid waiver providers of transportation.

Policy Outcomes. Implementation of this recommendation will support and encourage greater Medicaid Program participation and efficiency of transportation providers. In addition, evaluation of, and correction of the problem will increase access to other services for many frail elderly and physically and developmentally disabled persons, thereby supporting employment and daily life tasks.

System Barriers. It will be necessary to assess the cost and other resources needed to modify the Medicaid reimbursement and billing systems. In addition, the waiver amendment process is slow and will delay implementation of change.

Responsible Agencies and Action Steps. The Office of Medicaid Policy and Planning and the Division of Disability, Aging and Rehabilitation Services within the Indiana Family and Social Services Administration share responsibility for responding to this recommendation. Action steps include: evaluation of the Medicaid and Medicaid waiver reimbursement and reporting process and payment methodologies for transportation providers; identification of necessary system and process changes, development of a uniform payment methodology; and submission of a waiver program amendment to the Centers for Medicare and Medicaid Services.

Fiscal Impact. The fiscal impact associated with this recommendation will depend upon the administrative resources needed to revise the current reimbursement system. It is important to note that this recommendation is intended to be budget neutral since it does not request an increase in rates but rather consistency in how rates are calculated. If the rate calculations were the same in all Medicaid waiver programs and traditional Medicaid, then provider resources could be redirected to the provision of transportation rather than processing paperwork.

Targeted Completion Date. All aspects of this recommendation should be completed by June 30, 2003.

2.4 Provider Incentives to Increase Capacity

The Commission has developed four (4) recommendations that are related to provider incentives to increase capacity and that can be resolved quickly and with little or no fiscal impact or regulatory requirements. Each is described as follows.

Problem: Indiana's new Medicaid Home and Community Based Services Assisted Living Waiver is significantly under-utilized. It is not known if this is because of poor consumer and provider education, lack of providers, low rates, waiver program requirements that are too stringent, or a combination of these factors. After more than one year of operation and despite available funding, only a small number of people are receiving services through this waiver.

Recommendation 9: The Medicaid Assisted Living Waiver for Persons Who Are Aged and Disabled should be quickly evaluated to identify the participation barriers and then modified as necessary to successfully promote, develop, and support Medicaid assisted living waiver services to the fullest extent possible.

Target Population. Those who are affected by this change are aged and/or physically disabled Medicaid-eligible adults who are nursing-home eligible and who prefer to receive Medicaid services through the Medicaid Home and Community Based Services Program Assisted Living Waiver.

Policy Outcomes. Implementation of this recommendation should provoke the development of program changes that will increase the community and affordable housing service options available for those eligible, expand consumer choice, and improve quality of life. Since adults are served on any of the waiver programs at less cost than comparable institutional care, additional funds may be freed up to serve more persons for less.

System Barriers. The Assisted Living Waiver currently requires all participating providers to be licensed with the Indiana State Department of Health as residential care providers. And while there are good reasons for this requirement, it may limit the flexibility necessary to develop a broad base of providers. In addition, there is disagreement about whether Indiana's licensure requirement promotes a medical model of care over a social model of care (which emphasizes consumer independence and choice, as well as managed risk). Moreover, consumers and providers may not agree on the policy changes that are needed to promote greater waiver program participation. For example, consumers may prefer very specific physical environment criteria, while providers may desire some flexibility with respect to existing structures. Other system barriers may include the additional staffing and other resources needed to perform a comprehensive evaluation of program and design flaws and the subsequent modification and follow-through that may be necessary to ensure implementation success.

Responsible Agencies and Action Steps. The agencies responsible include the Division of Disability, Aging and Rehabilitation Services, the Office of Medicaid Policy and Planning, and the sixteen Area Agencies on Aging. Action steps needed to complete these changes are: convene a panel of consumers, providers, and state staff to evaluate participation barriers and any necessary modifications; evaluate and analyze current licensure requirements and available alternatives; evaluate communication and education outreach for consumers and providers; determine the approach needed to build consumer and provider participation; and if necessary, draft and submit a waiver amendment.

Fiscal Impact. Since the waiver program budget is fixed for each year, there is no fiscal impact associated with these changes. Rather, existing funds can be reallocated as needed. If, however, the licensure requirement is discontinued, then the Indiana Family and Social Services Administration must develop an infrastructure (comparable to that in place for the community

residential facility licensure process) for provider development, quality monitoring, and oversight, which will significantly increase program administrative expenses.

Targeted Completion Date. Begin a comprehensive analysis of provider and consumer concerns and program barriers immediately. Develop a comprehensive strategy by February 1, 2003, including the identification of any necessary waiver program amendments. Implement all changes by June 1, 2003.

Problem: Indiana's Medicaid Home and Community Based Services Waiver for the Aged and Disabled does not allow services to be provided in a congregate setting. This limits the affordable housing and service setting options available to waiver program consumers.

Recommendation 10: Fully define and develop the new congregate care¹⁰ option within the Aged and Disabled Waiver to ensure that this additional service and affordable housing component is viable and available.

Target Population. Those who are affected by this change are aged and/or disabled adults who are nursing-home eligible and who prefer to receive Medicaid services through the Medicaid Home and Community Based Services Program Waiver for the Aged and Disabled. It is, however, important to note that congregate care is a popular service setting among seniors and some providers, but much less desirable for adults who are physically disabled and prefer to live independently in the community. Therefore, it is critical that the development of a congregate care option does not in any way limit the choice of services available to consumers who do not prefer the congregate care setting.

Policy Outcomes. These changes will expand the array of community services and affordable housing available, particularly in rural areas of the State. This expansion can then be expected to improve waiver program access to qualifying consumers, expand consumer choice, and improving quality of life. Per federal regulation, adults must be served on any of the waiver programs at less cost than comparable institutional care, therefore freeing up additional funds to serve more persons for less.

System Barriers. Consumers and providers may not agree on the policy changes that are needed to promote greater waiver program participation. For example, consumers may prefer very specific physical environment criteria, while providers may desire some flexibility with respect to existing structures. Other system barriers may include additional staffing and other resources needed to perform a comprehensive evaluation of program and design flaws and the subsequent modification and follow-through that may be necessary to ensure implementation success.

Responsible Agencies and Action Steps. The agencies responsible include the Division of Disability, Aging and Rehabilitation Services, the Office of Medicaid Policy and Planning, and the sixteen Area Agencies on Aging. Action steps needed to complete these changes are: evaluate consumer and provider needs and participation barriers; develop necessary modifications; evaluate communication and education outreach for consumers and providers; determine the approach needed to build consumer and provider participation; draft and submit a waiver amendment, if applicable; and implement all program modifications.

Fiscal Impact. Since the waiver program budget is fixed for each year, there is no fiscal impact associated with these changes. Rather, existing funds will be reallocated as needed.

Targeted Completion Date. Begin analysis of provider and consumer concerns and program barriers immediately. Develop a comprehensive strategy by February 1, 2003, including the identification of any needed waiver program amendments. Implement all changes by June 1, 2003.

Problem: Many providers of services to Medicaid eligible individuals have difficulty receiving timely reimbursement from Medicaid for the services that they provide. Individual and small providers find the Medicaid reimbursement system especially cumbersome and difficult to understand. This complexity and difficulty in getting reimbursed quickly is especially problematic for small community providers who don't have the financial resources to survive long periods of time before receiving reimbursement. As a result, small community-based providers are hesitant to enroll or continue to participate in the traditional Medicaid or Medicaid waiver programs.

Recommendation 11: Since small providers are the key to building and sustaining an array of services in local communities so that consumers have choices, it is critical that the Indiana Family and Social Services Administration immediately examine the barriers to timely Medicaid reimbursement of services provided by small providers and focus their educational outreach on these small community providers. The Agency should also develop a streamlined payment process for small providers that will facilitate a timely and trouble-free payment. Waiver providers should be brought together to provide feed-back on the changes that the Office of Medicaid Policy and Planning is making in response to new HIPAA requirements. The group should have broad-based representation, including area agencies on aging, traditional Medicaid providers (both large and small), and providers of assistive technology, transportation, and environmental modifications.

Target Population. Persons most affected by this change are those who are enrolled in the Medicaid and Medicaid waiver programs and who need an expanded array of services in order to live in their communities, and the Medicaid-enrolled providers of service.

Policy Outcomes. Implementation of these changes will increase and maintain participation of small providers, thereby improving the array of services and supports available to consumers who choose to live in their communities.

System Barriers: Changes to administrative reimbursement policies and procedures, so that they are more responsive to the needs of small providers who don't have sophisticated billing systems and staff, may be resisted by agency administrators, billing and computer system personnel.

Responsible Agencies and Action Steps. The Office of Medicaid Policy and Planning and the Division of Disability, Aging, and Rehabilitative Services are responsible for evaluating and pursuing these changes. Action steps include meeting with a representative group of small providers and consumers of the services and supports provided to gain an understanding of their frustrations and concerns about the lack of timely reimbursement. Further action steps could include increasing educational and training opportunities for small providers to help them avoid likely barriers to timely reimbursement. After meeting with small providers and consumers, the Office of Medicaid Policy and Planning and the Division of Disability Aging and Rehabilitation Services should identify those barriers that could be modified or eliminated to enhance timely payment. An implementation plan, with timelines, should be developed.

Fiscal Impact. There may be additional costs associated with changing the reimbursement system in order to implement the recommended changes and focusing on increased education and communication with small providers and consumers.

Targeted Completion Date. Implement changes by May 1, 2003.

Problem: The current statute does not allow local taxing authority for Regional Transit Authorities. This lack of local funding options has deterred many areas from pursuing a coordinated service delivery mechanism that would allow for increased efficiency and mobility within urban/suburban areas and also in rural areas that are currently served by regional transportation service providers. In order for a local community to draw down Federal Transit Administration funds, it must provide a local match. With declining reimbursements and no authority to raise local taxes, many communities cannot overcome the funding barrier to start a regional transportation system. Urbanized areas have authority to create public transportation corporations (Indiana Code 36-9-4-10) but rural areas have no such corresponding mechanism.

Public transit systems are limited by city, county, and other boundaries. Many of the services, businesses, and employers are locating outside of these boundaries due to favorable taxing policies, thereby inhibiting the ability of people with disabilities to obtain jobs, attend appointments, and fully participate in all aspects of community life. The number of rural transit systems has expanded by seventeen new providers in the past five years and no new money is expected. In addition, rural transit systems utilize multiple, small pockets of funding to maintain their current systems. Funding from human service dollars, which is often utilized as match for federal dollars, is decreasing, further impacting the ability of public transit systems to maintain the current level of services. Thus, as the human services financial support decreases, so too does the ability to secure federal dollars.

Recommendation 12: The Governor and the Indiana General Assembly should examine and assess existing legislation aimed at establishing Regional Transit Authorities (RTAs) across the State to allow local taxing authority for the RTAs (I.C. 36-9-3). A determination of the fiscal impact relative to expansion of service should be thoroughly examined as part of this assessment.

Target Population. Those who would be affected by this recommendation are all persons who rely upon public transportation, especially the elderly and persons with disabilities.

Policy Outcomes. Implementation of this recommendation would significantly improve access to transportation, goods, and services, particularly for persons with low-income and who are considered to be at risk. In addition, employment opportunities could be expanded for individuals in need of or seeking transportation for employment-related reasons.

System Barriers: The complexity of this issue makes support difficult to obtain. Further, use of the term “taxing authority” is typically misunderstood and threatening, often leading to turfism and other forms of opposition. This change is statutory and will require legislation to be proposed and enacted.

Responsible Agencies and Action Steps. Those who are responsible include the Governor, the Indiana General Assembly, and city/county councils. It is anticipated that legislation will be drafted by a state legislator during the 2003 legislative session, therefore action steps include development of and consensus-building to support legislation, and Commission support for the proposed legislation.

Fiscal Impact. A determination of the fiscal impact relative to expansion of service should be thoroughly examined as part of this assessment. Depending on the local authority's response to the RTA securing taxing authority, a resultant tax increase at the local level may occur.

Targeted Completion Date. Complete by July 1, 2003.

2.5 Consumer Education

The Commission has developed one (1) recommendation that is related to consumer education and that can be resolved quickly and with little or no fiscal impact or regulatory requirements. It is described below.

Problem: The Department of Workforce Development oversees local resource centers that are intended to provide access to employment information and services for all persons. This information is, however, not always accessible for consumers and employers, thereby presenting a significant barrier in the identification of critical resources for those in need.

Recommendation 13: The Department of Workforce Development should continue to maintain all resource centers with up-to-date, local employment opportunities and services. This information should be as "consumer-friendly" and comprehensive as possible and should include current resource materials prepared by partner agencies and organizations.

Target Population. Those who would be affected by this change include all persons who are researching local employment opportunities and service options, especially persons who are at risk, unemployed, and underemployed.

Policy Outcomes. Implementation of this change will result in improved access and outreach for employment and service opportunities, assisting the consumers, the current and potential workforce, and the employers. The positive effects will also extend to the local communities by increasing the number of employed residents and energizing the economy.

System Barriers. Communication with partner agencies and organizations is at times complicated by the process by which information is disseminated within a particular agency or organization. Priorities within partner agencies and organizations vary, thus presenting a possible barrier to timely dissemination of information. In addition, the Department of Workforce Development often relies on these agencies to keep employment information current and up-to-date.

Responsible Agency and Action Steps. The Department of Workforce Development is responsible for updating the resource centers and collaborating with other agencies to obtain and maintain current and relevant information. The Department will also need to work with local partners to raise awareness of the information available and value of the resource centers. The action steps include the following:

1. The Department of Workforce Development should complete a review of what information is currently required to be included in the Department's resource centers. As indicated, this information should be up-to-date and comprehensive.
2. The Department of Workforce Development should ensure that resource centers are maintained up-to-date.
3. The Department of Workforce Development should identify responsibility (with the agency) for ensuring that resource centers are maintained up-to-date.
4. Once the above steps are complete, an outline of information required to be maintained in resource centers should be provided to all partner agencies and organizations for review and revision.
5. The Department of Workforce Development should identify responsibility for promoting website access to consumers and partner agencies and organizations.

Fiscal Impact. Limited administrative costs are anticipated in implementing the action steps outlined above.

Targeted Completion Date. The targeted implementation date for this change is January 31, 2003.

2.6 Consumer Choice

The Commission has developed three (3) recommendations that are related to consumer choice and that can be resolved quickly and with little or no fiscal impact or regulatory requirements. Each is described as follows.

Problem: There are several different state and federal housing programs, and most do not collaborate regularly. As a result, grant and other housing program opportunities (i.e. mainstream vouchers, Section 8 vouchers for individuals with disabilities) are lost or otherwise not pursued, and administrative resources are not used efficiently. Further, consumers are not informed about all available housing opportunities.

Recommendation 14: The Commission supports the application of a Real Systems Change mini-grant to focus on providing the administrative resources needed to facilitate and administer state/local application for all available federal/state funds to support housing initiatives (i.e. Mainstream Vouchers-Section 8 vouchers for individuals with disabilities). If the project is not funded by a mini-grant, the Indiana Family and Social Services Administration should identify other resources to fund this project.

Target Population. Those persons affected by this recommendation include those with low-income, including persons who are "at-risk."

Policy Outcomes. The impact of this change will be administrative cost-efficiencies among state and local agencies, improved consumer education and informed choice, and an increase in affordable housing options.

System Barriers. The most significant barriers for this recommendation are related to the identification of the entity responsible for pursuing mini-grant funding as well as to the development of a long-term plan to ensure resolution of the problem.

Responsible Agency and Action Steps. The Indiana Family and Social Services Administration is responsible for the administration, selection, and monitoring of the Real Systems Change mini-grants. The “hands-on” responsibility will rest with the grantee(s). Action steps could include the dedication of one or more staff to research and report on all available housing opportunities, and development of a training protocol for Public Housing Authorities, case managers, and consumers on how to access affordable housing funds.

Fiscal Impact. Assuming that this recommendation will be funded by one or more “mini-grants,” there will be no additional fiscal impact to the State. The fiscal impact of the long-term resolution of the problem is yet to be determined but will most likely result in additional staffing and administrative costs associated with implementing the recommendation. If this recommendation is not funded by a mini-grant, then the Indiana Family and Social Services should identify other resources to fund this project.

Targeted Completion Date. The implementation of this recommendation will depend upon the Real Systems Change grant timelines. It is anticipated that the mini-grant application will be made by April 2003.

Problem: Despite federal authority to do so, Indiana Medicaid waiver consumers have not yet been given the opportunity to choose, hire, train, and fire their personal care attendants. This opportunity has, however, been given to CHOICE Program consumers.

Recommendation 15: All applicable Medicaid Home and Community Based Services Waivers should include and implement the consumer-directed care service option.

Target Population. Those who would be affected include all Medicaid Waiver Program clients and attendant care providers.

Policy Outcomes. Implementation of this change can be expected to significantly expand the need for available caregivers. It would also increase the quality and utilization of services available to consumers by giving an array of choices in service delivery, thereby promoting the consumer’s ability to successfully “age in place” and to improve his/her quality of life.

System Barriers. Agency staff will need to develop and implement new processes to enable consumer choice. Organizations that provide services and supports to consumers in a more rigid and restrictive setting will be resistant to the shift of responsibility and decision-making to the consumer.

Responsible Agencies and Action Steps. Those agencies responsible for initiating this recommendation include the Office of Medicaid Policy and Planning and the Division of Disability, Aging, and Rehabilitation Services. Action steps include: development and implementation of a fiscal intermediary structure; development of a consumer and provider training and key advocacy groups; development of a quality assurance and monitoring protocol; and submission of a waiver amendment for all waiver programs.

Fiscal Impact. The fiscal impact of this change is expected to be minimal, since Medicaid rates for this provider group are already determined. There may, however, be some administrative costs associated with additional training needed to enable consumers to self-direct their care.

Targeted Completion Date. Implement by March 1, 2003

Problem: Persons with disabilities are often not adequately prepared for the workplace, since employment and vocation are not appropriately and comprehensively developed within the individual's person-centered plan, treatment plan, and/or individual education program (IEP).

Recommendation 16: The Indiana Family and Social Services Administration and the Indiana Department of Education should require inclusion of an age appropriate employment/vocational needs component as part of the person-centered plan/treatment plan/individual education program (IEP) for an individual receiving state funds or state-funded services, and/or services regulated by the State.

Target Population. Those who would be affected include any person receiving state funding or services regulated or funded by the State (i.e. any individual in an intermediate care facility for the mentally retarded, nursing facility, Medicaid waiver program, at-risk children within the school system, rehabilitation center, community mental health center, state mental health institution/services, etc.).

Policy Outcomes. Implementation of this recommendation will allow individuals to be better prepared for employment, making the employment experience more positive for both the individual and the employer. Additional benefits may include increased consumer independence, community tax benefits, decreased risk of institutionalization, various other positive aspects of a productive work life, and improved management of health care costs (i.e., evidence shows that when individuals with mental illness return to the workplace, the overall mental health treatment costs decrease, especially in the follow-along stages of employment¹¹).

System Barriers. There is currently a belief or mind-set that this recommendation is already being done, so a new training protocol and educational outreach will need to be established. Truly successful outcomes will depend upon the understanding and acceptance of state agencies, institutions, and case managers, as well as employer development at the local level. There also needs to be established an appropriate system to accurately monitor implementation and compliance and measure outcomes.

Responsible Agencies and Action Steps. Those agencies responsible include: the Indiana Family and Social Services Administration's Division of Disability, Aging and Rehabilitation Services, Vocational Rehabilitation Services, and the Division of Mental Health and Addictions; and the Indiana Department of Education. Action steps include: a review and necessary revision of agency policy related to inclusion of employment/vocational needs in the life-planning processes for identified individuals; development of a training protocol; and development of an implementation and monitoring plan. Community mental health centers that are not currently providing employment services should be encouraged to apply for a Real System Change mini-grant to fund a pilot program for these services.

Fiscal Impact. The immediate costs would be related to staff time necessary to ensure inclusion of the employment component in agency operating policies and administrative costs related to implementation and monitoring.

Targeted Completion Date. All aspects of this recommendation should be implemented by June 30, 2003.

Chapter 3: Two Categories of Additional Recommendations Not Yet Developed

As stated in the previous chapter, two other categories of barriers and proposed solutions have been identified. The first addresses short-term solutions that should be implemented quickly but that are accompanied by a fiscal impact and/or regulatory changes. And the second includes those solutions that are more complex, costly, or otherwise difficult to resolve and that will take more time to develop and implement.

3.1 Nine (9) Additional Short-Term Recommendations

Through the work of the task forces, the Commission identified nine (9) specific recommendations that have short-term solutions but that will require further development. The Commission has requested the task forces to begin development of these recommendations immediately. They will be reviewed by the Consumer Advisory Committee and the Commission and presented in the final report due to Governor O'Bannon in June 2003.

Each is presented below for reference only.

- State and local agencies and organizations responsible for economic development and workforce development should be required to provide greater business awareness in employing at-risk individuals.
- The State should increase funding for public mass transit.
- The State should review and modify legislation that limits the service area of a public transportation corporation to its taxing district.
- Representatives from the transportation “community” should be added to all Workforce Investment Boards (WIBs).
- The State’s service offering should be common across regions and agencies. Although local services will vary, the State’s offer should be consistent state-wide.
- A waiver for individuals with psychiatric disabilities to live in the community should be designed and implemented.
- Personal assistance as a service for Medicaid applicants and recipients in need of this service should be added to Indiana’s Medicaid State Plan.
- Research and training technical assistance centers to promote local collaboration and best practices should be developed.
- Website linkages with national databases for best practice reference should be established.

3.2 Ten (10) Additional Longer-Term Recommendations

Through the work of the task forces, the Commission identified ten (10) longer-term recommendations that require more complex and/or costly solutions. The Commission has requested the task forces to begin to develop these recommendations immediately. They will be reviewed by the Consumer Advisory Committee and the Commission and presented in the final report due to Governor O'Bannon in June 2003.

As with the preceding category of recommendations, each is presented below for reference only.

- A presumptive eligibility component should be added to the Indiana Medicaid Home and Community Based Services Aged and Disabled Waiver.
- Consumer access to the state systems (i.e., single point of entry, approval process done by the same person/place should be simplified and streamlined.
- Pre-admission screening for nursing home eligibility should be placed at the beginning of the system to assure that long-term care service options are identified at the time when transition decisions are made.
- A common point of entry for individual intake to access the entire system of support services should be implemented.
- Disability eligibility should be determined somewhere other than offices of the Division of Family and Children (if Medicaid moves to SSI determination, separate eligibility determination not required).
- A standardized state-wide rate for the same services should be implemented across all programs.
- A quality assurance program based on a consumer bill of rights should be applied across all programs.
- Medicaid disability eligibility criteria needs to be the same as Social Security disability criteria.
- Benefits should be provided to recruit and retain personal assistance service workers.
- Education, access, and utilization of the Early and Periodic Screening, Diagnosis and Treatment services provided by Medicaid should be expanded.

Chapter 4: Conclusion and Next Steps

This Interim Report is submitted to Governor O'Bannon for review and consideration by the newly-appointed Governor's Commission on Home and Community-Based Services. It includes a brief background of the relevant long-term care service delivery system issues, identification of the target populations, an overview of three federal grant initiatives, and foremost, an analysis of several critical recommendations that are essential for accomplishing substantial and lasting change in Indiana's long-term care service delivery system.

Sixteen (16) specific recommendations have been highlighted herein for immediate consideration and subsequent implementation. The Commission strongly advises the Governor and the legislature to take action on them. Each is critical in achieving the long-term care reform that has so long been envisioned by the Governor and so many others, and each is relatively simple to implement.

Another nineteen (19) recommendations have been identified and are scheduled for deliberation and analysis over the next six months. The Commission will continue to work through the five task forces and the Consumer Advisory Committee to evaluate the additional recommendations. They will be presented formally for the Governor's consideration in the final report due in June 2003.

For the remainder of its appointment, the Commission will: work with the Indiana Family and Social Services Administration to oversee the Real Systems Change mini-grant award process; develop focus groups; consider additional expert testimony; identify and document "best practices"; fully develop the Fact Book; develop strategies for capacity building; and define the benchmarks needed to measure change.

The Commission would be remiss if it failed to mention how much work remains to be done. For despite the activity and the level of progress that has been made by the Indiana Family and Social Services Administration and other state and local agencies over the past few years, Indiana continues to remain significantly behind most other states in re-focusing its scarce resources on the more desirable, less costly community-based service delivery options. Spending priorities in Indiana continue to focus on institutional care, and progress in resolving many of the more complex service delivery problems such as caregiver support, eliminating process and system barriers, understanding the needs and desires of consumers, and shortage of caregivers, for example, has been frustratingly slow. Furthermore, the common mind-set of traditional health care that is provided in traditional institutional settings and that favors medically cautious modes of care over one that relies upon consumer independence and freedom of choice continues to be extremely difficult to change. The Commission accepts this current reality but commits itself to being part of the solution.

The Commission ends this Interim Report to the Governor by restating how appreciative we are by the trust and responsibility given to us by Governor O'Bannon, and by promising to continue through June 2003 to work with the five task forces and with the guidance of the Consumer Advisory Committee. The Commission is committed to determine how best to embrace innovation and motivate solid and lasting change for Indiana's consumers of long-term care services. It is our goal to build upon the work of others by establishing partnerships between public and private, linking affordable housing and services, and creating a structure and process for consumer and provider outreach, all of which are vital for shifting the balance of Indiana's long-term care service delivery system.

Endnotes

¹ Dick Ladd, August 8, 2002 Presentation to the Governor's Commission on Home and Community Based Services, Indianapolis, Indiana.

² "Long-Term Care for the Elderly with Disabilities: Current Policy, Emerging Trends, and Implications for the Twenty-First Century", Robyn I. Stone, pages 5-6, Milbank Memorial Fund, August 2000.

³ OMPP Annual Report 2000, pages 10 – 11

⁴ "Statewide IN-Home Services 2000 Annual Report, July 1, 1999 – June 30, 2000", page 9.

⁵ The Centers for Medicare and Medicaid Services, or CMS, is part of the U.S. Department of Health and Human Services.

⁶ "Olmstead and Supportive Housing: A Vision for the Future", CHCS Consumer Action Series, Ann O'Hara and Stephen Day, Technical Assistance Collaborative, Inc., December 2001, page 5.

⁷ In other words, federal law requires that the Medicaid waivers serve only those persons who would otherwise be served in an institutional setting. Therefore, Indiana's Aged and Disabled waiver is only available to persons who qualify for nursing home placement.

⁸ Which would have been spent in the absence of the waiver.

⁹ Indiana Code 5-20-4.

¹⁰ The term "congregate care" for the Indiana waiver program generally refers to a community setting where persons live in close proximity to each other but do not share a common housing and services provider. This differs from the Medicaid waiver definition of assisted living, which refers to a setting where the provider is responsible for both housing and services.

¹¹ D. Perkins, Ball State University, February 21, 2001.